

CRS Parent Connection

Alabama Department of Rehabilitation Services



Volume 11, Number 3

Fall 2003

Meet Sharon Beech, Parent Consultant

Hello, I am Sharon Beech, the parent consultant for Children's Rehabilitation Service in our Jackson office. I was blessed with this opportunity in November 2002. Praise God, what a blessing. Although I am a new employee with CRS, I have been a part of the CRS family for many years. Let me introduce you to my three children.

Fourteen-year-old Cody works hard in school and at sports. He still finds time to be the muscles and our handyman around the house. He has some orthopedic issues we are addressing, so it's comforting to have CRS help me make informed decisions.

Coleman, 12 and all boy, is absolutely amazing. I draw so much strength from his determination to manage his diseases instead of his diseases managing him. Coleman was diagnosed with systemic juvenile rheumatoid arthritis on his first birthday; he was diagnosed with Crohn's disease a few years later. He is hearing impaired and absolutely loves to sport his Kelly green hearing aid. When he chose his hearing aid I said, "Coleman, it's so bright it will be very noticeable." He responded, "I know, Mom. I want everyone to know I can hear." Hmm, what we can learn from children when we just listen. Coleman has been in the hospital more times than I can remember and currently receives Remicade treatments every six weeks at USA Children's and Women's Hospital. At the hospital, he always has a smile, a few jokes and stories of his past weeks' experiences. I love to watch him brighten another's day as he brightens mine.

Olivia Joy is my 9-year-old "Prissy." At 15 months, she was diagnosed with polyarticular JRA and scoliosis, and a few years later with fibrous dysplasia. She is a go-get-em gal and she definitely gives her brothers a run for their money.

If you ever have the chance to meet her, be prepared to visit a while—she likes to talk more than I do.

I'm happy to have the opportunity to introduce you to my family. We face and deal with many issues, the most difficult being how many times and how close death has been to Coleman.

As parents of children with special needs, we have ideas, hopes and dreams for our children, as does every other parent. We can help make these hopes for our children's futures a reality by collaborating our efforts and sharing our experiences. We can learn from each other.

I truly look forward to serving you. We have great things in store for us: a Family Resource Center, Parent Advisory Committee and many other services. Please come check out our new building in Jackson and visit a while. Consider being a part of our Parent Advisory Committee. I would love to hear your ideas of how we can serve you and your family.

Sharon Beech, Jackson CRS (251) 246-4025 or 1-800-283-8140 Email: sbeech@rehab.state.al.us



(See summer fun pictures of Sharon's children on page 7.)

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Parent Connection is a complimentary

Newsletter (published by Children's Rehabilitation Service) for families of children with special health care needs. The goal of this newsletter is to increase communication and share information about children with special health care needs and their families. The newsletter reflects a family-centered theme throughout and serves as a forum for family members to share information, thoughts, feelings, concerns, etc. Nothing printed or implied in this publication constitutes an endorsement by the Alabama Department of Rehabilitation Services.

This material is available in alternate formats upon request. Alternate formats include braille, large print or audio tape and may be obtained by calling the phone numbers listed above.

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From The Director's Chair



Hello Everyone!

Well as we once again wind down from Summer and get ready for Fall, it always seems that there are just too many things that have to be done and too little time to do them. Schools are starting a new school year, and preparing for that is always a challenge with getting all the right supplies, getting all the right clothes, adjusting our schedules one more time and making sure our kids are settling into their new school routines.

Fall 2003 has an added item that we must all take care of that will make this year very different. We will be voting on Governor Riley's tax and accountability package. All of us have a voice that we need speak with on September 9th in the form of our individual votes. I believe that September 9, 2003 is a critical point in Alabama's history and will have a profound impact on the children and families of Alabama for many years to come, no matter the outcome of the vote. Each of us must decide for ourselves if we believe Alabama can move forward without additional money to provide services to our citizens. Amendment One contains all the parts of the accountability and tax package and we are being asked to vote once for "all or nothing." The part about "all or nothing" that concerns me is it just may actually mean *all* or *nothing* in state services to many Alabama families. Please educate yourselves as much as you can about this extremely important issue and make your one vote count on September 9th and record your choice!

This is also the time of year that state agencies budget for next year's services. CRS, like many other state agencies, continues to see our state dollars cut by proration and further eroded by rising costs of services and the rising costs of just doing business—paying rent, utilities, supplies, etc. We have reached the point that continued loss of funding will result in cuts in the services we are able to provide to the citizens of Alabama. In an effort to prepare for this possibility, CRS will be developing a service cut contingency plan during the next year. We will be actively asking for consumer and family input about what these cuts should include and how they should be carried out if they become necessary.

One of the ways we will be seeking family input will be through the CRS State and local parent advisory committees (PAC). There are local PACs across the state that are facilitated by our local CRS parent consultants. If you are interested in becoming a CRS local PAC member and you are not familiar with the PAC in your area, please contact your local CRS office or contact Susan Colburn, CRS state parent consultant, at 1-800-846-3697 for information.

(Continued on page 4)



YOUTH NEWS

WORDS FROM THE YOUTH CONSULTANT

I am back again to discuss all of the latest topics, especially those that relate to youth. On August 8-9, 2003, a CRS Youth Advisory Committee (YAC) retreat was held in Birmingham, AL at the Wynfrey Hotel. The retreat gave YAC Members the opportunity to obtain relevant information and get to know each other a little better. Samantha Manning, a YAC Member, said, "I definitely enjoyed it. I really enjoyed seeing old friends. The information was very helpful. The packet gave a lot of beneficial information, especially from a job standpoint." The committee members also had the opportunity to share their concerns with guest speaker Ms. Bonnie Spears, who works with the UAB MCH LEND Project to educate professionals on how to work effectively with youth. When asked how she felt about the discussion, Sarah Floyd, another YAC Member, replied, "I enjoyed it! It was very beneficial and I felt our voices got across a lot clearer because people were listening to us instead of us just talking amongst ourselves. We also had a lot of fun!" According to Hannah Floyd, "I think it was very informative. There were some things we discussed that I didn't know about. The retreat was very fun." Overall, the CRS Youth Advisory Committee Retreat went very well. Collectively, the YAC members accomplished a lot while enjoying each other's company.

2010 TRANSITION WORKGROUP

On July 9, 2003, the 2010 Transition Workgroup convened in Clanton, AL with over 40 people present, including youth, to discuss Alabama's plans for goal #6 of Alabama's 2010 Action Plan for Children and Youth with Special Health Care Needs. The goal states: "All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life." I am very pleased with the number of young people who were present at this meeting. It is very important for us to provide our input as it relates to policies that will affect us at some point in our lives. More information will be provided about the Transition Workgroup at a later time.

Jennifer Thomas, CRS Youth Consultant

YLF NEWS

On July 31, 2003, the National Center on Secondary Education and Transition held a teleconference call entitled *Youth Leadership Forums Developing Leadership Skills in Youth with Disabilities.* Jennifer Thomas, CRS Youth

Consultant and Angeline Pinkard, of the Alabama Governor's Committee on Employment of People with Disabilities, participated in this call to further discuss the details of Alabama's Youth Leadership Forum (YLF) that is held annually in Troy, AL. A transcript of the teleconference call can be found on NCSET's website at www.ncset.org.

The applications for the Alabama Governor's Committee Youth Leadership Forum for High School Students with Disabilities, which will be held on June 6-10, 2004, are now available. The DEADLINE is February 20, 2004. If you are interested in receiving an application, contact: Linda Graham, 1-800-441-7606, lgraham@rehab.state.al.us or Jennifer Thomas, Applications may also be picked up at Children's Rehabilitation Service offices or downloaded from the ADRS Website at www.rehab.state.al.us.

New Website

The MCHB (Maternal & Child Health Bureau) Healthy & Ready to Work National Center is now "at your service" at www.hrtw.org. The mission of the HRTW National Center is to create changes in policy, programs and practices that will help youth with special health care needs transition to adult health care, while encouraging work and independence-raising expectations..



The HRTW National Center, colocated in three key organizations nationwide, operates as a Virtual Project Enterprise. This telework team of established leaders in the fields of health care, interagency collaboration, youth/

family leadership, electronic dissemination and evaluation brings diverse strength and inovative partnership between and among public, private and consumer organizations.

A national focal point for the Health Resources & Service Administration, HRSA/MCHB's HRTW initiative, the center will advance the Healthy People 2010 goal of "improving the health and quality of life of youth and young adults with disabilities and reduce the disparities that exist for this population when compared to youth and young adults in general."

(Continued from page 2)

CRS is in the business of providing services to Alabama's children with special health care needs and their families, and that is just what we plan do with the resources we have available. The fact is that currently our resources are shrinking and it is only prudent that we plan for the worst and then do everything that we possibly can to see that the worst never happens. We need and will be asking for your help over the next year in developing a service cut contingency plan. *Together we will make a difference!!!*

Until Next Time!Cary Boswell

(Continued from page 3, Youth News)

Alabama Transition Conference

I attended the Alabama Transition Conference in March. At this conference I participated in discussions concerning parents letting their children with disabilities become more independent in managing their regular visits to the doctor, and the worries that children with disabilities will have to face in the future. The Transition Conference gave those attending the confidence to achieve their highest goals.

By Jenny Oveson, YAC Member

ADRS on the Web

If you haven't logged on to the Alabama Department of Rehabilitation Services (ADRS) website at www.rehab.state.al.us in a while, you are in for a pleasant surprise. The website has been completely redesigned to assist you in being better informed about the many services available through ADRS. The Children's Rehabilitation Service (CRS) pages are full of easy to access listings of available programs, resources and important events. On the Family Resource Center page you can locate videos, audiotapes or books on a topic of your interest. The current editions of the CRS Parent Connection newsletter are also found here. The Family Events Calendar will inform you of coming special events. These are just a few of the many useful pages at www.rehab.state.al.us.

Internet Respite Resource

Families across the state will soon find care for loved ones at the click of a button. Relief for Alabama families caring for a person with a disability is now found on the Internet. The Alabama Lifespan Respite Resource Network (Alabama Respite) can help connect families with respite care programs that meet their specific needs through a new interactive website. Respite care is temporary relief that allows families or caregivers to take a break from the ongoing responsibilities of caring for an individual with special needs, regardless of age or disability.

While the current website provides information about the network's services, a new feature will allow caregivers to

conduct specialized searches that will locate respite care providers in their community. The interactive databases, available throughout the state, will allow families to search the collection of respite programs by county, disability and/or age. This exciting new website became available for public use on July 1,



2003. Alabama Respite is constantly updating the database as new respite resources are located. Visit the website at www.alabamarespite.org. A database of funding opportunities to start new or support existing respite resources throughout the state is planned for the near future.

Alabama Lifespan Respite Resource Network was established in 2000 to develop a coordinated system of lifespan respite care that gives caregivers and families a single point of access for respite information and resources. Their mission is to raise awareness about the need for respite within the state and increase the number of resources available to families and caregivers in Alabama. Alabama Respite is an affiliate of United Cerebral Palsy of Huntsville and Tennessee Valley and is funded partially by the Alabama Council for Developmental Disabilities (ACDD) and the Caring, Daniel and Hillcrest Foundations.

If you know about respite services in your area that are not included on our database, or if you are interested in starting a respite program either in your church or community, please contact Alabama Respite at 991-0927 in the Birmingham area or toll free across the state at 1-866-737-8252 (RESTALA).

By: Linda Lamberth Alabama Lifespan Respite Resource Network (205-991-0927), www.alabamarespite.org



God's Grace

I am wonderfully made by God's hands, The work of a Master oh so grand. No, I am not perfect according to you all, But my life is a testament of His call. For I have a purpose in this place, One of joy, hope, love and grace. You shouldn't feel sorry or cry for me, For I'm as happy as a girl can be Because I have God right here at my side, To help me through this earthly ride. I am happy to be part of His plan, Which involves every woman, child, and man. For I know that God is in charge Of everything in my life, small and large. His way I know is right; He is my comfort day and night. Although I'm small and can not talk, I understand how we are to walk— Beside our Lord who will help us grow To be more like Him so that people will know That God is our saving Grace And we should live to seek His face. Yes, I do have special needs and may not be considered wise,

So consider this when you're with me
Because through my eyes the Lord can see.
He knows what you do and what you say;
He's present like this in special ways.
So listen to me and be sure to pray
For yourself and others at the end of the day
Because I want us all to be in that Heavenly place,

But according to my Lord, I'm an Angel in disguise.

Knowing that we have experienced God's Grace.

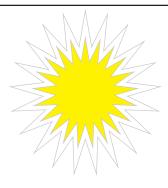
A special message from one of God's little Angels - LeeAnna Grace Written by her mother, Jill Cunningham © 2003



LeeAnna Grace is 18 months old. She has chromosome 8p deletion syndrome. This syndrome is extremely rare and there are very few documented cases. LeeAnna has global growth and development delays. She weights 15 pounds and just began rolling over at 18 months. She has a gastrostomy tube for nutrition and eats very little by mouth. She was born with birth defects involving her hands and feet and has had several corrective surgeries.

LeeAnna is our little angel. She is so sweet and so content with her life. She smiles and laughs and claps her hands when she hears music. She is such a joy and has been a wonderful blessing to our family. We thank God daily for sending her to us.

Summer Fun





Jenny Horsley, Jackson, AL, had her dream of riding on a motor-cycle fulfilled by two local motorcycle clubs. Jenny was presented with her own leather vest and then given a ride through the streets of Jackson, stopping at the Dairy Queen for ice cream.

Megan Miller, Wilmer, AL, arrives at Camp Adventure. CRS was pleased to sponsor Megan and many other CRS children to attend camp this summer.

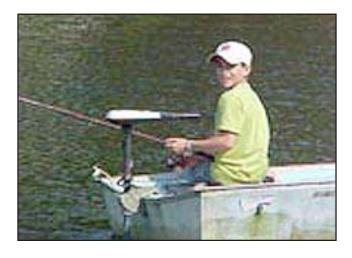






Ryan Colburn, Montgomery, AL, and the Frazer Memorial UMC Youth Choir on tour in Ohio.

We welcome pictures of your family for the newsletter. Pictures may be sent to Susan Colburn, Children's Rehabilitation Service, 2129 East South Blvd., Montgomery, AL, 36116; or emailed to scolburn@rehab.state.al.us. Please include permisssion to use the picture in the CRS Parent Connection newsletter.





Coleman and Olivia Beech, Jackson, AL, fishing and kayaking in July.



Kayla Pollard, Huntsville, AL, plays mermaid princess in her pool. Known as "Boo," her brother and sister think she is a mermaid with attitude.



Jenny Oveson, Mobile, AL, enjoys summertime with her family.

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|------------------------------------------------|
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| Clip & Mail to: Susan Colburn |
| Children's Rehabilitation Service |
| 2129 East South Boulevard |
| Montgomery, AL 36116 |



Parenting Today

Happy New Year

By Tracy Rao

It's that time of year again. Time to start making new year resolutions, not the diet and exercise type, but new school year resolutions. You know what I am talking about—I will keep better documentation of the school's activities regarding my child; I will help my child be more organized with homework and extracurricular activities; I will follow all the advice of Pam and Pete Wright (Wrightslaw: Special Education Law and From Emotions to Advocacy); I will get along better with the school this year; and I will be a better IEP team member.

We are beginning our sixth year of working with basically the same IEP team for my child which began when he turned three and transitioned from Early Intervention to the local school system. Our relationship with our child's school is not perfect, but probably few such relationships are. Sometimes it's difficult to make sure our child's IEP is being implemented properly while maintaining a good relationship with the school system. Overall, our experience with our child's school has been pretty good, and through the years we have learned a few principles we try to follow when working with the school.

R-E-S-P-E-C-T— First and foremost, we try
to demonstrate and gain respect. We recognize
our child's educators are professionals and
know many things about educating children
that we don't. We also realize they don't know
everything and neither do we. That's why we
team together to plan our child's education.

Through the years we have listened to their suggestions and ideas regarding our child's education, and they have listened to us as well. They understand we plan to be involved and provide input in our child's education. We don't expect them to have all the answers. Therefore, we have educated ourselves on the laws and

best practices regarding educating our child. We have a mutual respect for each other's ideas.

2. Understanding Circumstances While Staying Focused—We know our school system has limitations: time, money, and educational. That's life. Due to these limitations we have had to compromise—sometimes making major compromises. However, we have certain expectations from the school in educating our child regardless of educational restraints and in a few basic areas, they know we will not be swayed.

When we do disagree, we try to focus on the issue, not the people. This is not always easy but it is very important if we are to keep the team relationship going. We try to stay focused on our goal of providing our child with the quality education he needs to live an independent life. We know we are not enemies, even though sometimes it may feel that way. Understanding doesn't always come easily, and we may not always see each other's viewpoint, but each side always tries to listen.

3. Communication—Communication is the key to our relationship. If issues arise that need our attention, we try to address those issues as quickly as possible. Frequent communication with our child's educators is important in making certain the IEP is being implemented properly. Both sides have to be available and open to communicating with each other.

Communication can be just a note from the teacher on a worksheet letting you know your child did well that day. It could be sharing some new information on upcoming conferences with your child's educator. Sometimes we make a quick phone call just to clarify homework instructions. A brief, regularly

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scheduled meeting every couple of months is a great opportunity to talk and see what issues crop up. With all communication, we always try to be courteous, considerate and firm when needed. I try to keep a communication journal referencing when I may have forgotten what was said. (Okay, I don't write everything in the journal, but that makes a great new school year resolution!)

4. Good Parenting—Somehow I have subconsciously made "good" synonymous with cooperative and agreeable. Through the years I have learned that being a "good parent" doesn't mean automatically agreeing and cooperating with everything the school wants. By using the principles above, I have learned that standing up and expressing my views about what I believe is right for my child, even when it isn't what the school wants to provide, is being a "good parent."

The same goes for your child. Being a "good" child doesn't mean he always cooperates and agrees with you. Part of the quality education that will allow my child to live independently includes learning respect, understanding circumstances while staying focused, communicating, and standing up and expressing what he believes is right for him, even when it isn't what we think.

5. Remembering Our Roles—I am, after all, just a mom and my children are just kids. It is important that I take time just to be a mother to my kids and allow them to be children. Staying on top of all the latest technological advances, late-breaking legislative news, and most current medical research would be nice, but who would have time to play?

Good tuck with an your new school year resolutions.

Tracy Rao and her husband, Dan, are the parents of two children, Aaron and Megan. Tracy has developed a program called Plugging into Empowerment that teaches families necessary skills to effectively obtain supports and services in inclusive settings. She is a community resource with TechNet and a 2000 Partners in Policymaking graduate. Tracy believes parents and professionals working together and learning from each

Questions Parents Ask About Schools

Parents wanting to know more about how they can help their children excel in school can find the answers to those frequently asked questions in a new publication "Questions Parents Ask About Schools."

In 16 reader-friendly pages, this booklet provides research based tips that cover a range of topics for parents or caregivers with elementary and middle school children, including:

- Preparing your child for school
- Knowing what to expect from your child's kindergarten teacher
- Monitoring school work
- Working with schools and teachers effectively
- Helping your child with reading and homework
- Ensuring that your child's school is safe and drug free.

"Questions Parents Ask About Schools," has been compiled into one single text with both the English and Spanish translations and is available online at www.ed.gov/Family/agbts/Questions. For a paper copy, please call the Department of Education's publications center at 1-877-4Ed-PUBS with identification number EKH0124P. One order per customer please.

The Achiever, Office of Intergovernmental and Interagency Affairs, U.S. Department of Education, May 1, 2003

Exceptional Parent Magazine

The September 2004 issue of *Exceptional Parent* magazine has many articles of interest to parents of children with special health care needs. The article "Making a Difference All Through the School Year" talks about including students with special needs in the regular classroom. Two technology-related articles are "Technology Column: Assistive Technology Resources for Students With Mild Disabilities" and "IBM and Technology for Children with Special Needs." With a new school year beginning, parents will find these articles very helpful. Also in this issue, Susan Addision begins writing a series of Early Intervention articles in support of families of infants and toddlers with special needs.

You can read the Exceptional Parent magazine at your local CRS office Family Resource Center, or to subscribe for your own copy, go to their website at www.eparent.com.



A National grassroots network of families and friends speaking on behalf of our children with special health care needs.

FAMILIES AS ADVOCATES

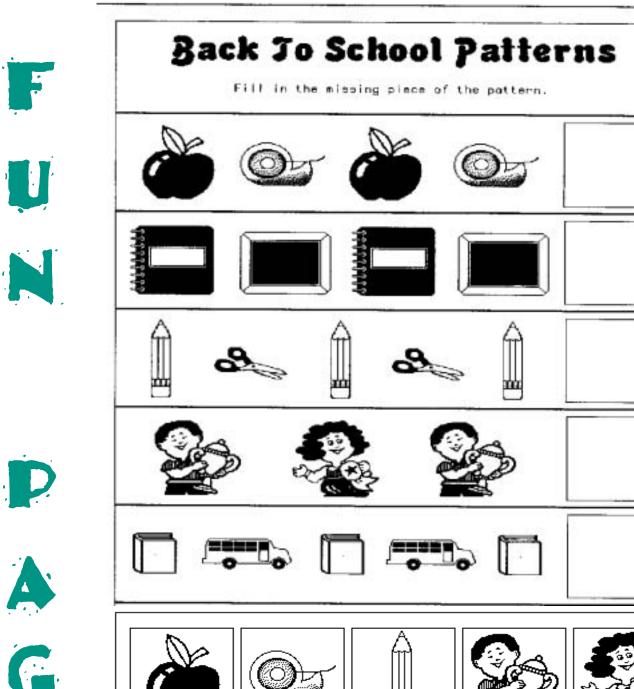
BEING A HEALTH ADVOCATE FOR YOUR CHILD WITH SPECIAL HEALTH CARE NEEDS

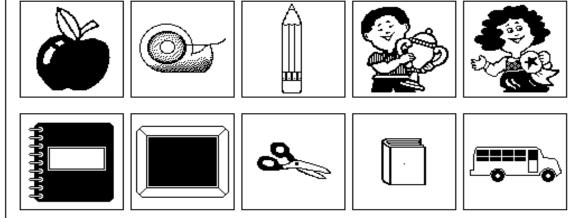
Parenting a child with special health care needs is not easy. The thousands of members of Family Voices, most of us parents of kids with disabilities or chronic conditions, want you to know you're not alone on this amazing journey. We're there, too. And we know that the sooner we parents become knowledgeable and strong advocates for our children, the smoother life becomes for our entire family. Our advocacy tips focus on health issues, because that is the mission of Family Voices. But you can use these ideas at your child's preschool, child care center, classroom, in the community, and with your extended family and neighbors. Family Voices also has materials that describe how to advocate for other children by improving public and private health systems serving youngsters with special needs. We all begin, however, with one child.

- Believe with all your heart that your child, like all children, is wonderful - even when she or he gobbles up so much of your time and energy. Tell all the world about this precious gift! Remember, though, that your child with special health care needs is not the heart of your family, but a part of your family, sage advice from veteran mom, Florene Poyadue.
- As soon as possible, make contact with another family who also has a child with special needs. Hearing from another parent who never sleeps, feels inadequate and is also frightened about the future will change your life. We know it's not easy to talk with a stranger about your child, but it's worth it. Most communities have a parent organization that matches experienced fathers and mothers with new parents. Some groups bring parents together around a certain diagnosis, Cerebral Palsy, for example. Parent groups give peer support free and help you learn all about this new world.
- Find out everything you can about your child's diagnosis from your pediatrician, early intervention program, parent group, local library and state program for children with special health care needs. Surf the Internet, where every imaginable diagnosis has a website full of information and resources. If you lack a computer or don't know how to surf, ask for help. Every community now has a location with free internet access. Family Voices has a list of Internet addresses.
- Learn about the hospitals, pediatric specialists, therapy centers, equipment banks, early childhood programs, and state and private agencies that your child will use. Ask other parents for advice about where to get the best care.
- Keep records and take notes of all phone calls, doctor visits, insurance bills, Medicaid notices, and forms

- related to your child. Request copies of everything. Put this paperwork in one place a box in the kitchen, a notebook, a bedroom drawer.
- Become an expert on your child's health insurance plan, whether it's through your employer or Medicaid, especially the benefits paid for by the plan. Make sure you ask lots of questions about how your health insurance works and about any special seminars that might help your child.
- Insist that all your child's providers, from pediatricians to social workers, practice familycentered care which acknowledges and supports families as they raise their children in their homes and communities.
- Develop strong partnerships with health and other professionals in your child's life, so that you can work together and use the expertise and skills each of you brings to the care of your youngster. It's especially helpful to have one professional who knows you, your family, and your child very well and who will advocate with you as a partner.
- Know that YOU are your child's best advocate. No one else will do the job as well. Use all the information, contacts, friends and skills you have gathered to practice your advocacy firmly, but with kindness and humor. As your child grows up, teach her or him to be an advocate, or prepare a sibling or friend to do so. Because you won't be around forever. In the meantime, it's wise to take care of yourself.
- Ask Family Voices for help. Call us toll free (1888-835-5669) or visit www.familyvoices.org to find brochures, books, and websites about linking parents, family-centered care, family-professional partnerships, fathers' networks, information in languages other than English, support groups, and more.

NOW, GO FORTH AND ADVOCATE!!!







Sept. 18-20

December 10 - 13

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Orlando, FL; Contact: www.wcdexpo.com

Out What's Ahead

World Congress & Exposition on Disabilities, Orange County Convention Center;

October 3 Technology Expo, Eufaula Community Center; Eufaula, AL

October 3 A Child with Hearing Loss: Communication, Amplification & Education,
Mobile Marriott; Mobile, AL; Contact: AL Ear Institute, 205-879-4234

October 23 - 25 Conference on Career Development & Transition: A Season for Change; Roanoke, VA;
Contact: www.dcdt.org/conferences

November 19 - 21 Early Intervention & Preschool Conference, VonBraun Center; Huntsville, AL;
Contact: Jeri Hughes, 205-823-9226 or JBH50@aol.com

November 19 A Gathering of Families & Friends at the AL Early Intervention & Preschool Conference,
6:00 P.M., Hilton Grand Ballroom; Huntsville, AL; Contact: Diane Roberts, AL Early Intervention
System, 334-281-8780

Annual TASH Conference, Chicago Hilton & Towers; Chicago, IL;

Contact: Kelly Nelson, knelson@tash.org or http://:tash.org